

## Getting support

Significance of support and advice for being able to manage your life having become deafblind

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# EXPERIENCES FROM PEOPLE WITH DEAFBLINDNESS

*- a Nordic project*

## **Getting support**

Birgitte Ravn Olesen and Kirsten Jansbøl



*“The aim is to become master  
of your own home”*

# **Significance of support and advice for being able to manage your life having become deafblind**

A five-year Nordic project  
focusing on the personal experiences of persons  
with acquired deafblindness

*Birgitte Ravn Olesen and Kirsten Jansbøl*

Translation by Ability Top Translations



Information Center for Acquired Deafblindness, 2005

## **The Nordic Project**

### **Six booklets**

- Theory and methods
- Receiving a diagnosis
- Getting support
- Being active
- Getting an education and work
- Narratives of everyday life

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willingness to share their experiences.

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they put into the project.

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project possible by their financial support.

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This theme booklet is one of a series of six booklets resulting from “The Nordic Project on collecting the experiences of persons with acquired deafblindness with a progressive disability”. Twenty persons with acquired deafblindness from Norway, Sweden, Iceland and Denmark have annually, over a five-year period, participated in interviews about the practical, emotional and social consequences that a progressive hearing and visual disability has on such aspects as changes in the prerequisites for communication. In the booklets the project is referred to as The Nordic Project to underline, that the whole project speaks about the experiences of people with acquired deafblindness in the Nordic countries – though not Finland.

For more about the project organisation, method and theoretical basis please see theme booklet No. 1, “Theory and methods”.

## **About deafblindness**

All the persons in this study have all become deafblindness as a consequence of Ushers syndrome, which appears as a combination of hearing loss – which can vary from moderate to total deafness – and the eye disease, retinitis pigmentosa, also known as RP, which gradually destroys the retina. Please refer to theme booklet No. 1 to learn more about Ushers syndrome, hearing loss and RP.

Persons with Ushers syndrome are either deaf and have sign language as their native language or are moderately to severely hearing impaired and have Danish, Swedish, Norwegian or Icelandic as their native language. At the same time they have an ophthalmic disease that progressively restricts their vision over a period of several years. Some become blind, but many preserve some residual vision into advanced age.

Some of the participating deafblind persons understand and define themselves as deafblind, but others understand and define themselves as deaf persons with a serious visual disorder, hearing impaired with a serious visual disorder or severely visually impaired with a serious hearing disorder.

They all have considerable difficulties in communicating, acquiring information and being independently active due to the dual sensory impairment, even though the majority

have some degree of vision and even though the participants with moderate to severe hearing impairment all speak the national language.

For the sake of clarity, this study refers to the participants as “persons with acquired deafblindness or the “deafblind”.

**The titles of the theme booklets from the project are:**

1. Theory and methods – Project outline, theory, methods and empirical data
2. Receiving a diagnosis – Experiences of having a disability and being diagnosed
3. Getting support – The significance of support and advice for self-sufficiency
4. Being active – To be participatory despite a progressive disability
5. Getting an education and work – Getting an education, holding a job and being organised
6. Narratives of everyday life – Narratives about living with deafblindness



# Introduction

In this booklet, we focus on the experiences of the acquired deaf-blind of the support and advice that they receive. The questions to the informants are based on an expectation that people experience receiving useful support or advice when they meet other people who can help to advance them with their own goals in their lives.

This means, for example, that a young deaf-blind woman who is offered extra lighting in her college room does not necessarily see this offer as support. It may be that she does not recognise that she needs extra strong light, but it is also possible that her need for her college room to be similar to those of her companions who have weak cosy lighting is so dominant that she would prefer to be compensated in other ways. Useful advice is a piece of advice that is based on what is important for the person seeking advice. It sounds obvious, but it can be very difficult for the professional to find out what the most important thing is for the person he / she is facing. It can similarly be frustrating to know that there are possibilities of facilitating everyday life for the acquired deaf-blind that this particular person does not wish to hear about or relate to.

The aim of this booklet is to show the types of support and advice that the acquired deaf-blind have found to be useful and with which they have problems. The stories of receiving support and advice show that both needs and experiences are very different. This booklet first of all introduces the concepts that we have found to be relevant in our work with the subject of this booklet. It is not necessary to know these concepts to be able to gain benefit from the informants' stories, so if you are most interested in the stories, you can jump forward to page 17.

The concept of "mastering" is already presented in the booklet on "Receiving a diagnosis". It will therefore briefly be described as a basis for linking the acquired deaf-blind person's possibilities of taking charge over their situation with different types of support that may be offered by people around the acquired deaf-blind. The starting point is in the concept of "competence to act", since this concept includes focus on the acquired deaf-blind person's possibilities of obtaining support and advice in relation to his / her own goals.

## Competence to act

For Karsten Schnack from Denmark's Pedagogical University, the concept of "competence to act" is linked to the concepts of "experience", "authority" and "generation". (Schnack, 1993:7)

"Experience" is about the way in which you perceive yourself and your situation on the basis of previous experiences in life. "Authority" is about the extent to which you see yourself as decisive in your own life, and "generation" is about the reasons for the importance of the way you act in concrete situations.

Schnack points out that there is a difference between behaviour and action. Behaviour is something on the outside that we can observe and influence people into doing, while an action is targeted, determined by an intention. If you get a person to drink 5 glasses of water a day without that person having any idea of doing this, you have influenced the behaviour. However, if we are talking about an action, that person must have an intention behind his / her action. She (sic) must want to achieve something by drinking water.

Seen in relation to the acquired deaf-blind, a consultant or a teacher can motivate a deaf-blind person to obtain a blind person's stick and perhaps over and above the purchase get the person concerned to go on a course in using it. However, if that person himself / herself cannot see a purpose in using the stick, it will probably never become a part of that person's daily life.

People's self-worth is increased when they find that they can use their perception of the world to influence and control their own situation. Competence to act is characterised by personal skills on three levels:

- Concrete actions that are expressed through proficiencies and performances
- Knowledge that is expressed through reflexivity and knowledge-related potential
- The self and meaning level, which covers identity-related potential.

(Jensen, 2002)

You can thus get people to change their behaviour by manipulating or indoctrinating them, but as a rule, they will not continue with a type of behaviour into which they have been manipulated and, says Schnack, it can never be the task of the teacher, the

educationalist or the consultant to inoculate a determined behaviour. Here, the sole task is to support the individual and what she is facing in achieving her own goals.

The task of the professional is thus to strengthen the client's competence to act, his / her experiences of and resources for being able to act purposefully, starting from his / her own situation and his / her own needs.

Schnack points out that competence to act is a generation ideal. The means that you cannot say that some have and others do not have the competence to act. Instead, we must see competence to act as an aim for all, and that some people possess this to a greater extent than others in relation to different areas. The level of competence to act is to a large extent determined by the individual's own experience of having been influenced and the experience of being able to do something to change his / her situation. (Schnack, 1998)

This means that all people have the competence to act, and that everyone possesses the potential to develop their competence to act. Some experience that the things they believe and do mean something. They can act purposefully in relation to fulfilling their needs, while others instead have experience of initiatives being taken over their heads. If you primarily have such experiences, the development of experiences of purposeful action in relation to own needs must begin on a small scale. Several researchers have pointed out how giving responsibility to people who do not have experience to act competently in relation to own goals can contribute towards experiences of fiasco and defeat. (Thomsen, 2000, Hisen and Sørensen, 2000)

A person who has become deaf-blind and who does not have her own experience of taking initiative will probably have to be supported in that her need for a fixed interpreter is reasonable and understandable and she will be helped all the same to persist in this desire, even if the formal guidelines state that you cannot ensure such an arrangement.

Teachers, educationalists, social workers and others who are able to develop competence to act as an ideal for contact with clients therefore tell us of the way in which they meanwhile experience coming into conflict with the established assistance apparatus, since they work to support the client's own view of his / her needs before being loyal to "the system".

The concept of competence to act is thus a generation ideal that everyone possesses, but that some have greater experience of displaying than others. It is important to bear in mind that performance is what is seen, the tip of the iceberg, while the potential lie beneath and can be mobilised and developed. (Jensen, 2002)

# Levels of involvement

Roger A. Hart is a psychologist and has for many years worked with the involvement of children in development projects within areas like health and the environment. He has developed the “Participation Ladder” (Hart, 1996), that the Danish researcher into health educationalist Bjarne Bruhn Jensen has translated into a Danish context. We have chosen to adapt Jensen’s model so that the categories are relevant in relation to discussing the acquired deaf-blind people’s involvement in decisions concerning their lives.

## The involvement ladder

Decision area Participation form	Definition of needs	Elucidation of prerequisites and resources for an individual and in society	Choice of action / strategy	Evaluation / Follow-up
Client initiative Joint action				
Client initiative Client action				
Professional initiative Joint action				
Professional information Client accepts				
Client not involved				

The model must be read such that on the lowest levels there is a very small possibility of influencing the client, while on the uppermost levels, there is a strong possibility of influence. Note that the second to top category is called “Client initiative / Client action”, while the top one is called “Client initiative / Joint action”. Bjarne Bruhn Jensen, who is working with health education in a school context, should be asked the reason for this. Here, he sees that the students achieve the best prerequisites for achieving the competence to act when they can cooperate with the teacher to gain ideas and do something with them. Does the same still apply to contact between the professional and the acquired deaf-blind? Does it yield greater possibility for action when the client’s own initiative is backed up by the professional than when the client himself / herself takes the initiative and attempts to carry out his /her own idea alone in life?

The horizontal axis distinguishes between different decision areas where participation may be relevant. Does the formulation of needs state, when clarifying the resources that will be mobilised for the needs to be satisfied, when choosing the strategy or in the follow-up, that the acquired deaf-blind person has co-determination?

The model can be used as an analytical tool when we are to analyse the informants' assertions on the way in which they concretely experience being met in the professional system. In brief, concepts such as "competence to act" and "involvement" in contact between client and professional can help to focus on the conditions that are significant to the way in which the individual acquired deaf-blind person can act in his / her daily life.

# Mastering

Another way of grasping the single individual's way of handling challenges and conflicts is the concept of mastering. This concept can describe people's ways of relating to and coping with the situations they meet in their lives. There may be situations that lead to compromised well-being, unpleasantness or threats against integrity. The American psychologists Lazarus and Folkman distinguish between two forms of mastering, both of which we use in our everyday life:

**Problemfocused mastering**, which includes active actions with the intention of solving a problem. This is used both when you believe that something can be changed and when you accept a given situation and work with your own feelings-related reactions in connection with this. In short, when you see the problem before your eyes and then act. Problem-focused mastering implies that you identify a problem and find ways of changing, solving or eliminating the problem.

This can take place through actions in practice or through cognitive restructuring where the person consciously changes perception, thoughts or ambitions in relation to the problem.

**Emotionally focused mastering**, which is not aimed at solving the actual problem, but rather at changing the experience of the problem. It may, by denying that the problem exists, be that you give up relating to it or avoid your feelings and abuse others because you are in a given situation. However, emotionally focused mastering can also be constructive. It may be that the person is seeking care to be able to cope with her feelings, that she insists on the positive view of the situation or that she is seeking a deeper meaning from the situation she is in.

(Lazarus and Peopleman, 1984)

Just as competence to act is not something you have or do not have, nor is there anyone who always acts in a problem-focused way while others are consequently emotionally-focused when they are in a stressful situation. In relation to mastering, you must be aware that being able to take charge of your situation happens by means of a process. What may be experienced in a situation as right, e.g. driving away your fear in order not to break down, can in another situation, e.g. when you are together with people you feel safe with, feel wrong. In this situation, it may feel right to talk to others about your fear

to find out how to cope with it. In the example, the first batch talks about emotionally focused mastering, whilst it later becomes problem-focused mastering.

The key is to bear in mind the procedure. Taking charge of a situation means managing to endure it for the moment. There is no implicit expectation that the chosen strategy will work in the long term.

Conversely, it is clear – also with the acquired deaf-blind – that some people have experiences that put them in a better position to master the challenges they meet. The Israeli sociologist Aron Antonovsky points out the individual's "sense of coherence" – "experience of context" – as crucial to whether the individual can mobilise strengths to cope with difficult situations. If the individual experiences his / her life generally, in particular the concrete situation, as understandable and predictable rather than chaotic and uncertain, and as manageable and controllable rather than experiencing themselves as victims of circumstances, we are talking about an individual with a strong "experience of context". One final element that characterises the individual with this experience is that she can see the meaningful aspect of her life and of the concrete situation, and feels safe with her own significance and value.

Antonovsky characterises an individual as having a strong "experience of context" if he / she is conscious of his / her feelings, in a position to describe them and not to feel threatened by them. These feelings will be recognisable and be experienced as personal and culturally acceptable. There will therefore not be such a great need to disregard their existence. They are experienced as a suitable reaction to the situation you find yourself in.

Conversely, the individual with a weak "experience of context" will be someone who is inclined to lay the blame on external causes when she experiences problems. She will talk about "the failure of others" or bad luck that is following her. However, writes Antonovsky, evasion of responsibility leaves a resentful feeling of discomfort in the individual (Antonovsky, 2002, 165).

Seen in relation to the mastering concept, it is clear that people with a strong "experience of context" will be inclined to use problem-focused mastering, while people with a weak "experience of context" will often use an emotionally orientated mastering strategy.



The same applies when we look at individuals' competence to act. People with a strong "experience of context" will have experience of action to achieve their goals. They want to recognise that they are authoritative and competent, and their actions will be aimed at achieving their goals.

Competence to act, involvement and mastering are now presented as key concepts. It is therefore time to look more closely at the stories of the acquired deaf-blind.

## Obtaining support when you need it

We have in other booklets dealt with the way in which living with a progressive impairment implies that life causes crises to arise where you must revise activities, relations and / or experience of yourself. In such situations, many informants express that they have needed professional support and many also experience having received this.

The support can take many forms. We will differentiate here between:

**Information and practical support**, which primarily concerns support to gain insight into the possibilities that exist to relieve or compensate your impairment, and support to get aid organisations to function in daily life.

**The focus is on emotional support and support for self evaluation**, where showing interest and confidence to be willing to listen, to allow room for reflection and the possibility of comparing with others in the same situation.

We will firstly look at the informants' stories of the types of support they have experienced needing and having received. When we have examined the experiences of information / practical support and emotional support respectively, we will return to the concepts of competence to act, involvement and mastering to be able to discuss the way in which the informants' different "experiences of context" and life experiences are significant to the types of support and advice they need.

### **Information and practical support in everyday life**

Information and practical support are about ensuring that the acquired deafblind person receives information and practical assistance in relation to their financial and social situation. Here, it is a question of the family's compensatory organisation of everyday life, about the local authority's case handling and about the informants' experiences of all the practical assistance bodies they meet.

### **Information and practical support in the family**

The informants talk about different ways of gaining practical support from the family. Anders, who is 21 and has a medium-level hearing and visual impairment, tells us how his parents have always focused more on him than on his older brother:

*“There is an almost implicit acceptance in the family that I need my parents more than my brother does. I need support and help in more areas than he does, and this seems very obvious. I don’t believe that this is perceived as a problem by any member of the family.”*

Anders expresses recognition of his particular situation and its consequences for the family. The fact that he is clear about his particular needs, and feels that they are accepted by the rest of the family, is without doubt of great significance to his positive experience of himself and his possibilities. Many others, particularly those who are deaf, relate the way in which communication with family and the surrounding environment was limited in their childhood. Only when they get to a school for the deaf for the 5 - 6 age group do they gradually experience being able to communicate on equal terms with other people. Here, on the other hand, they have to live with being a long way from their parents and brothers and sisters. Such childhood experiences can provide far less “experience of context”, significance and meaningful life.

The informants who live as a couple or in a family today tell us indirectly about how they obtain practical support in everyday life. This occurs when the spouse drives them to events, when the spouse primarily has to take responsibility for the parents’ meetings at the school, and when the spouse clears up, as she is the one who can see fluff on the floor. More informants describe it as a big strain not to be able to contribute to the family’s practical chores on an equal footing. It is then also thought provoking that two of the three younger male informants with small children have wives who during the project have suffered from serious depression that has led to long-term periods of sick leave. In one case, a traffic accident was the direct cause, but there is something to indicate that these families are more vulnerable than it immediately appears.

Johan, who is 52 and has medium-level hearing and visual impairments, says how having a guide dog has helped to make him more independent from his spouse:

*“I see it as an advantage to get a guide dog early to develop the cooperation and be able to feel safe when you go out, particularly when it’s dark. I can now go out and go on walks, go down to the sea, I can go to places where I haven’t been able to go for the last few years. This is the way I’ve chosen to solve my limitation problems and to get out again. My wife can steadily cultivate her interests and I avoid having to ask her.”*

Some families are in different ways in a position to receive practical support outside of the core family. Three younger male informants who all have their own family have chosen to live close to their own – and in some cases also the spouse's – parents. A fourth chooses as an adult to move away from his friends in the city and back to the town where his parents live. An example of the way in which the acquired deaf-blind person's parents can be involved in everyday life is with Ottar, who is 46 and has a medium-level hearing impairment and a very serious visual impairment. He has consciously chosen to live close to his parents. The two families share among other things newspapers so that Asger's father drops by daily, and has for many years done preparation homework with the couple's three children.

Another example of the way in which the family and other close relations can be very important is with Borghild, who currently lives alone. She is 54 and has a serious visual and hearing impairment. She has a large and versatile network consisting of their daughters, an older man in the neighbourhood, a boyfriend, neighbours, female friends and old colleagues, and it is totally natural for Borghild to draw on these relations. She therefore does not need a contact person or other practical public assistance, since in her network it is natural for members to help one another where they can.

Not everyone, and particularly not the single deaf and deaf-blind person, has such close and strong family relations, to which we will return. More informants mention that they often feel misunderstood by their closest family. In this context, we are searching for written information on Usher Syndrome that can be given to family, friends, neighbours, doctors and case handlers. Several women with adult children say they feel that their children lack insight into their impairment. Perhaps a slowly progressive impairment means that the family constantly falls behind in relation to adapting to what the acquired deaf-blind member of the family can and cannot do. A consequence of this may be that information to relatives, both written and verbal, must be given on a running basis in line with the progress of the acquired deaf-blind person's impairment. It is not enough to invite them to courses or distribute information to relatives all at once.

Several informants also lack genetic information on Usher Syndrome. They live with an uncertainty concerning heredity in relation to their own children and grandchildren, which they do not know how to deal with.

## Information and practical support from friends and colleagues

Tonje, like several others, has a network that offers practical support in everyday life. Tonje is 20, deaf and visually impaired. She tells us how she uses her friends in everyday life. She suggests that they follow the way to events, since she can cycle after them. When she is at a disco, she goes with a female friend to fetch drinks to avoid bumping into people, and when she has seen a film at the cinema, she lays a hand on her boyfriend's shoulder so she can tell when they are going up or down when they are leaving. Tonje usually does not tell others about her visual impairment, but says that "in the back of their minds, they know very well that I have visual problems, and so they don't ask." Tonje is obviously in some situations, e.g. together with her boyfriend, in a position to receive support without saying why she needs it.

Many informants receive important information through their network. It may be private friends, others impaired persons who they meet in their association activities or a third party altogether. Hilde, who is 44 and has a medium-level hearing and visual impairment, for example invites the caretaker of the property where she lives for coffee a few times a year and asks him to tell her the news about what is going on in the home. Hilde's action is a good example of problem-focused mastering; she needs information on what is happening around her and has difficulty gaining this information by seeing and hearing it, so she invites a key person for coffee.

Anders is very categorical concerning where he receives the best support. He points out their friends, who are hard of hearing:

*"My friends are in the same situation as myself, so what comes from them is bound to be reasonable. It's as simple as that. Those I learn the most from, without exception, both socially, professionally and in every respect, are others with impairments."*

Other informants also tell us that they receive practical support from both other acquired deaf-blind persons and from friends and work colleagues who see and hear, but also that it can be difficult to get support. It applies to all informants that light at cosy meetings is a problem. It is great practical support to ensure that there is a great deal of light, but in the Nordic Countries, we generally link comfort with weak lighting, above all flickering candlelight that makes it impossible for the acquired deaf-blind to find their way around. Brian, who is 32 and has a medium-level hearing and visual impairment, tells us of the problem at his workplace:

*“At Christmas, when everyone was sitting enjoying themselves in the canteen, I lit the light as I was going to get my mug. At that point, several people said “Oh, can’t you put that out, it’s not very cosy.” I said that I needed the light and I actually became irritated. At the same time, I was sorry... it’s easy to believe that I am normal, but in certain situations, my behaviour is not normal. People forget that I have this impairment, and they also say to me “your behaviour is so normal that we forget.” So only you yourself can speak up, say if you have a requirement. I find it irritating that it would almost have been easier to have been blind. There wouldn’t have been much to discuss... I don’t pay attention to my own needs in all situations. I should have done that much more.”*

Here, Brian points out a dilemma. On one hand, he values the fact that his colleagues do not remember that he has an impairment, and on the other hand there is a great lack of consideration shown to him. He also concludes that he constantly has to practise expressing his needs, since this is a prerequisite for others to be able to show the necessary consideration. When Brian points out his needs, he behaves with authority, he shows with his action that he expects consideration to be shown for him. He can do this, as he has experienced that he is worth showing consideration for. Brian’s action is an expression of “problem-focused mastering”. He acts in relation to his needs, namely to get better light. Brian’s further comments bear witness to the fact that it is not easy to act like this. He says that he was sorry because he values the fact that his colleagues perceive him as “normal”, but he ends by saying that he will practise making his needs visible.

All informants express differently the fact that they are in constant discussion with themselves regarding the requirements for consideration from others that it is reasonable to set. Having these considerations may be seen as an expression of social competence. At the same time, it is clear that only when the acquired deaf-blind person’s needs become visible to others is it possible for them to think about the consideration that they wish to show.

### **Information and practical support from the public system**

Contact with the public system covers a large number of contacts. These include the whole of the professional assistance apparatus within both visual and hearing impairment areas, including deaf-blind consultants, local authority case handlers, interpreters, home helps, contact persons and many more. The more advanced the visual and hearing impairment, the greater the need for support and advice.

## Local authority case handlers

Some informants say that they experience contact with their local authority case handler as important, since their financial scope is largely determined here. At the same time, this is the contact that they experience as being the poorest. There is a large turnover among personnel, and knowledge of the Usher Syndrome is limited or non-existent.

Some of the problems in connection with receiving practical support are about obtaining information on what you can apply for regarding support and where you must apply for what. The less vision and hearing you have, the more difficult it can be to get through the systems. The deaf-blind consultants therefore play a key role as coordinators. They can with their overview and insight into the field help to ensure that the individual acquired deaf-blind person receives the necessary practical support. We then also ask about satisfaction with the deaf-blind consultants, but the input is not enough, particularly in relation to those with the poorest vision and hearing, which we will return to in the section on emotional support.

Marie, who is 48, deaf and has a serious visual impairment, tells us how her deaf-blind consultant has supported her in establishing good contact with the local authority case handler. Marie and her deaf-blind consultant have together asked to meet the case handler, where they have spoken about Marie's impairment and agreed that communication between her and the case handler must in future be via e-mail. Marie says:

*"I think it's very positive that I have a good case handler here in the local authority. If I have some major problems that I don't know how to solve, I can explain this to my social worker, and if I can't manage that, I use the deaf-blind consultant. This is what we've agreed."*

If we look at Marie's story, it reflects cooperation where each of the three parties offers cooperation. The case handler puts aside time for the meetings and is interested in understanding the citizen sitting opposite her; the deaf-blind consultant takes the initiative and functions as negotiator, and the acquired deaf-blind person undertakes the responsibility of reporting to and from and involving her deaf-blind consultant if problems arise. At the involvement stage, we are at the third level here, i.e. a professional initiative that is followed up by joint action.

Several informants say that they lack such a coordinating function in relation to their own local authority. Johan, who through all interviews has expressed a desire to regain

his link to the labour market, does not feel that there is practical support that can help him. He understands that it is the local authority's task, but does not experience anything being done, since the one hand does not know what the other one is doing:

*"That superior function, the unifying entirety that we are sitting here talking about, the advice function, I wish it reached across all professional borders."*

Martin, who is 44, deaf and has a very serious visual impairment, says that his case handler in the local authority at the last meeting said that there must now be fewer coordination meetings. In the future, it will be more up to he himself to get in contact with different bodies. He is not satisfied with this at all. Mads, who is from the same country, and who is also deaf and has a serious visual impairment, conversely receives information that a plan must now be made for the next 5 years and that coordination meetings will be held. There are therefore substantial differences within the same country. Mads says:

*"So I now avoid having to go from person to person ... we must make a plan for the school, an interpreter and a contact person and I will participate in that planning."*

He is very much looking forward to this arrangement, as he has experienced the exact consequences of no coordination having taken place. His number of weekly periods with a contact person has been more than halved, as he did not use all of his hours last year. According to the informant, incorrect information was to blame. He did not manage to appeal against the decision before the deadline had expired, and must now wait a year to have his expensive weekly contact person periods increased.

It is clear that the informants in the above examples need support in contact with their local authority. We see at the involvement stage, where this is an example, the way in which the informants themselves are seeking professional support to both formulate their needs and to realise the needs in desires for resources that can lead to further action. They are in other words looking for a professional initiative for coordination to be able to increase their possibilities of acting competently in relation to their own goals.

Monica, who is 43, deaf and has a very serious visual impairment, gives a good example of the fact that there can also be a problem with the acquired deaf-blind not knowing the logic of the local authority systems:



*"I contacted my case handler, as I wanted more hours with my contact person, but I felt that she was so curious – she wanted to know everything she could about what I wanted to use the contact person for. When I came home, I contacted the chairman of the deaf-blind association to tell him about my experience. We discussed it and I found out that case handler may have been able to use this information to be able to clarify that I actually had a need."*

After this clarification, Monica returned to the case handler and explained her needs in detail, whereupon she was given a greater number of weekly periods. In this situation, Monica uses problem-focused mastering. She becomes annoyed about it, she experiences the case handler's misplaced snooping into her private life, but rather than giving up or being abusive, she seeks advice in relation to her experience, advice that puts her in a position to have competent cooperation with the case handler.

### **Professionals within the field of visual and hearing impairments**

Where contact with the local authority case handler is often experienced as difficult, the experience of parts of the professional system that are directly aimed at the acquired deaf-blind is often positive. We see in Brian an example of the way in which contact with a hearing educationalist can help you to pursue your own goal as a person who has become deaf-blind:

*"I was pretty sceptical about rehabilitation, but she succeeded in convincing me ... it was fantastically useful, and as far as I can understand, I should be able to receive a greater disability supplement than I currently receive. Today, I receive the lowest. She informed me of the assistance you can obtain – also at the workplace – and of the rights and obligations you have."*

Again, an example of the way in which a professional, in spite of an initial opposition, gets rights and action possibilities introduced that put the acquired deaf-blind person in a better position to pursue his / her goals.

One single informant criticises the offers available to the acquired deaf-blind as being focused more on care than on help to help themselves:

*"It isn't care and safety that the younger people need, it's something more robust. It must be something that's more adapted to the individual's situation, interest and desire, and*

*an individual plan must therefore be made to realise some specific goals ... something is lacking within the social area for younger people, also in the association (for the acquired deaf-blind)... you are after all treated almost like a pensioner."*

The informant is looking for individual support and advice that can help to increase his competence to act. He has goals and direction, but feels that the system's offer is aimed solely at looking after him. This criticism is important. Several others do however talk about the way in which, through work placements and offers of training and through courses for the acquired deaf-blind, they experience receiving support to pursue their personal goals.

One young informant, who is still at school, notes that she largely cannot use the advice of others. Nevertheless, she remembers that an educationalist at the school has a visual impairment. She has spoken a little to this educationalist. What was special about the conversations was that the informant experienced that they exchanged experiences on an equal footing:

*"She's a bit older than me and has told me about her youth. It's more about exchanging experiences than good advice. I've thought about whether or not I'd follow good advice if someone came along with it, but no, I don't believe I would."*

There are others informants who also mention professionals with whom they have had particular contact. One mentions the deaf-blind consultant as someone special, since it is she who knows the informant's needs and has the relevant information. The consultant's interdisciplinary contribution leads to something special. Another one mentions her eye specialist with whom she has built up a reliable relationship to for many years. She also – based on restructuring – has to have a new specialist, which worries her. It is important to meet another person who over and above her professional insight is in a position to see you as a unique person and show a particular interest.

The final example of a very successful cooperation between the acquired deaf-blind person and the professional system is with Borghild.

Borghild's story begins on a course for the blind, where she through conversation with others in the same situation progresses to wanting to return to the labour market. Her desire to be linked to the labour market is followed up by a social worker within the field

of blindness. Together, they inquire at her previous workplace, and she ends up with a further 8 years on the labour market.

Borghild's story shows the way in which she through conversation with like-minded people gained courage to formulate the desire to return to the labour market. The need is defined by Borghild, but by virtue of solid backup from a social worker, they were able to carry out a successful strategy - a good example of a client initiative that is backed up by joint action.

Interpreters and contact persons must also be counted in the group of professionals within the field of visual and hearing impairments. We will deal with these groups briefly below in the section on aids, while their important role is dealt with in the booklet called "Being active".

## **Aids constitute important practical support**

Information and practical support act as pretty rapid aids. It is a matter of obtaining information on existing aids, of being offered them, of obtaining them and having them installed and of learning to use them.

IT has become enormously important to nearly all of the acquired deaf-blind in the project. The medium is so flexible that it can be adapted to the individual's needs and everyone, from close friends and relatives to informants, has taken on the medium and uses it for a large number of activities where e-mail and information searching on the Net are the most dominant. Apart from IT, there is the mobile telephone. You can always have this on you to use for SMS. The mobile telephone's background light on the display can also function as a notice board when those with weak vision have to communicate with others in the dark.

As with all other good aids, you rapidly become dependent on them. Therefore, frustration concerning repairs, lack of training in their use and similar also forms a part of the informants' description of the support in connection with aids.

### **Obtaining information on and being offered aids**

It is immediately relevant here to differentiate between two types of acquired deaf-blind people, i.e. the group who have accepted their impairment and wish to know to about and make use of aids, and the group whose hearing and visual impairments are still not that advanced and who have a more ambivalent relation to their impairment.

In the group first-mentioned, there is general satisfaction with the offer of aids, while several express the desire to obtain better knowledge of new aids. It is implied that everyone knows about the most important aids such as hearing aids and white sticks. Information on new arrangements that can facilitate daily life is demanded instead. Here, we see that the way in which they receive information is too random, and that they have to apply themselves. As one informant says, "I have to know that it exists before I can give an opinion on it."

Some acquired deaf-blind tell us that they discover new aids through friends and acquaintances, and then themselves search for further information. Again, the acquired

deaf-blind person with a weak social network is particularly vulnerable if he does not gain information through contact with other acquired deaf-blind people.

One informant tells us what you can do in some countries to spread information on aids. Here, meetings are arranged where the acquired deaf-blind meet one another and have the possibility of trying out new aids.

Generally, the acquired deaf-blind who have a clarified relation with their impairment are satisfied with information and offers of aids. One exception is Safeve, who is 63 and has a medium-level hearing impairment and a serious visual impairment. He himself chooses to buy a computer and associated equipment, since he will not discuss the reasonableness of his needs or wait for what is, in his opinion, long-winded case handling.

The group of acquired deaf-blind people with a more ambivalent relation to their own visual and hearing impairments is certainly not as satisfied.

Here, we find among others two younger family fathers with medium-level visual and hearing impairments. Petter, who is 33 and has medium-level hearing and visual impairments, says that he lacks insight into his rights. He has experienced not being able to get financial support for the things he asks for, but has discovered that he can receive support for things that he simply had not considered applying for. An example of something he would like a grant for is trips with the family. They cannot simply take places from cancellation trips, but must ensure that the conditions at the destination are suitable for him to be able to function there. Such support cannot be granted. Conversely, he can receive support for taxi rides, which he did not know, as he has always cycled and taken the bus.

*"I once had a taxi grant to travel to my leisure activity, but I said a polite no thanks to it again, as I wanted to decide for myself how to get home. I could have rung and said that I wanted to go home a bit later, but I just think that it's a bit wasteful. It costs money, and so much has to be saved, so I don't feel inclined to do that. I'd rather manage on as little as possible, but on the other hand, I'd like to be able to receive help if something arises where I need it."*

Petter therefore carefully considers his needs and thereby the types of help that he finds reasonable to accept.

Informants with minor visual and hearing impairments often express ambivalence - they find it difficult to ask for support. When they nevertheless do ask for help, they experience that their needs do not fit into the support entitlement categories. This ambivalence may also be a matter of not wanting to be dependent on aids. Johan is asked whether he has ever been given advice that he could not use, and answers:

*"Yes, I have, as regards aids. As late as last Friday, when I was at the eye clinic where the eye specialist said that if I thought it was too difficult to read, I could obtain a CCTV. So I said stop, I can read well today. Upgrading to bigger aids is not for me. I think you must be careful with that; there is not a problem with technology today, but it must occur in line with your need."*

A similar assertion comes from Anna, who is 50 and has medium-level hearing and visual impairments:

*"A visual educationalist was supposed to come and help me to set up a CCTV screen, but no fewer than three visual educationalists turned up. They began to discuss light and lamps, but I was only to have a screen. Professional people are sometimes too eager to put forward suggestions for many other things. Luckily, I have the capacity to back out."*

This assertion indicates that the informants in the above situations do not experience receiving information about the possibilities that they can express an opinion on. They instead experience the professional taking over and defining their needs, and thereby the offer of aids become overwhelming.

When the information on aids is not experienced as a pressure, but purely as information, it is easier to relate to. Johan says:

*"I went over to the Institute for the Blind and spoke to a consultant. I was introduced to the different aids. I didn't know anything about it, so that was good enough. Even if I didn't need aids at that time, it was still good to know that they existed and the possibilities still existed if I experienced problems. Yes, it is obviously difficult as I have nothing to write home about."*

Here, things seem to be going well. It is difficult to relate to aids, as you at the same time have to relate to the fact that your impairment is progressing and that there are

new things that you cannot do or have to use aids to be able to. Talk about aids is therefore not neutral, but on the contrary provokes feelings. This is probably also the reason why more informants are complaining at the same time that they do not receive the systematic, continuous information on aids that they need as a result of their progressive impairment, and at the same time they say that they experience pressure when the system's employees inform them of the existing aids.

We will return to this problem in the section called "Dilemmas in relation to information and practical support".

### **Obtaining aids**

If we take a minute to consider interpreters and contact persons as aids, their substantial significance to the individual's competence to act in everyday life must be mentioned here. Having qualified interpreter assistance and a contact person available is absolutely crucial to whether or not the deaf and acquired deaf-blind people in particular can demonstrate and develop competence to act. These functions are treated in more detail in the booklet on "Being active".

We heard previously that the acquired deaf-blind people who have a clarified relation with their impairment are satisfied with the information and the offers of aids. There is sometimes less satisfaction with when and how they will receive the aids.

Martin, who during the project lost his last remaining vision, gives a good example of how difficult it can be to obtain the aid he has been granted. He applied to receive a mobile telephone, since he would be able to use this to communicate with other deaf people. It was granted immediately, which Martin was told. Martin has since heard no more. His deaf-blind consultant contacted the aids centre after a few months and was told that the mobile telephone was ready for collection from there. She asked them to deliver it directly to Martin's workplace and expected that Martin would have it delivered here. This did not happen, though. The mobile telephone is now at the counter at his workplace, where the deaf-blind consultant finds it, as she has to meet with Martin. She tells him that it has come, he fetches it and is very pleased. Nine months have passed from when he applied for it and was granted it.

Others have similar experiences. Marie says:

*“The aids centre irritates me. There has been much criticism of the fact that they make promises over and over again. I obtained a Braille machine (Braille Light) with guidelines in English. I asked for them to be translated. They promised and promised, but over a year has now passed. I contacted them and tried to explain the situation, and they promised again. That irritates me.”*

The characteristic of Martin's, Marie's and others' stories is that they themselves must be active, know the system well and constantly toil to obtain the things that they have already been granted. It requires a high level of self-worth to be able to know the systems and insist on your rights in these systems. Something indicates that Marie has developed competence to act in relation to asking for help and maintaining her needs, even though it can also be difficult to make an impression. Conversely, Martin appears to be passive in relation to his problem. He formulates a need that is immediately recognised, and he is granted a telephone. Hereafter, it is only the deaf-blind consultant who acts on his behalf. He demonstrates a low degree of competence to act in relation to having his need for a mobile telephone fulfilled.

### **Learning to use aids**

Several informants state that it is easier to have aids granted than to have support granted to learn to use them. Some of them have experienced in particular that it takes time before a granted computer has the relevant programs and they themselves have gained an insight into how to use them.

Lise, who is 48 and has medium-level hearing and visual impairments, also mentions dissatisfaction with the aids centre. She was granted a computer, but not training to use it. Only when she herself finds out that she must apply for training under her own auspices does she succeed in obtaining this.

Martin has been granted training in connection with procuring a new computer and Net connection. A blind teacher understood this, and since Martin himself is deaf and at the time of training had very limited residual vision, he experienced being completely cut off. He has since received training in another context.

### **Aids in general**

The above focuses on a number of problems in relation to obtaining and using aids. When the informants tell us about their lives, they speak indirectly about the meaning of



aids - particularly computers, hearing aids and visual aids – as regards their possibilities of being active in everyday life. This conversely also means that they are dependent on these aids and therefore have limited tolerance towards waiting times, misunderstandings and similar, which means that the aids do not function well.

Several say that they experience long-windedness on the part of the system. They experience that their own and the professionals' evaluation of their needs are different, and they lack acceptance of their own ideas or suggestions (for example, if these are more expensive than a standard solution). Finally, several point out that they lack training in the use of aids. It must be mentioned that there are also many informants who express satisfaction with the systems linked with aids.

Some informants point out that the competence is not always in order in relation to their needs when they apply for practical support. Several mention that they find that there are capable professionals in both the blind and the deaf fields, but that few have insight into having a combined hearing and visual impairment.

In the stories on experiences with aids, we see a clear dividing line between the following:

Informants with a strong network and a strong "experience of context" are generally satisfied with the system. They receive information on aids in many ways - through their personal network, through the member pages for the hearing and visually impaired and for the deaf-blind, and through participation in courses, club meetings and other things for the respective impairment groups. Generally, this group experiences being able to assert its needs and be taken seriously. Anders mentions his own responsibility for the cooperation:

*"Generally, it is good for you yourself to know what you want and need. This applies in every respect, and also that you need to express a certain firmness. Without this, I think it's easy to be disregarded, even if not through ill intent."*

Ottar emphasises meeting up, so that the people who make decisions on his behalf know who he is:

*“They cannot decide that my impairment is not that serious without meeting me. They do not know that it is that serious because I do hear well on the telephone when I talk to them. I took my contact person with me and she (the case handler) asked questions ... My contact person repeated them many times and she could see that I couldn’t hear as well as she had thought, and I therefore got what I’d applied for.”*

Informants with a weak network and a weak social situation in all respects, typically single people, find the system difficult. At the same time, it is this group that has the greatest needs. They experience not obtaining or randomly obtaining information on aids and rights. They also have limited experiences of formulating their needs and experience action being taken above their heads.

## **Dilemmas in relation to information and practical support**

We have now looked at the informants' stories about the way in which they experience that information and practical support helps or prevents them from living the life they desire. Family, friends and a large number of professionals are mentioned as significant people.

On the way, we have looked at different problems in relation to the way in which particularly the professional assistance bodies can act if the aim is to develop the individuals' experiences of acting competently in relation to own goals. In this collection, we will point out two dilemmas that arise from the informants' stories.

Firstly, we will focus on the professionals' dilemma in relation to the acquired deaf-blind who have an ambivalent relation to their impairment. We then focus on the role of the professional when negotiating about aids.

### **Ambivalence in the acquired deafblind is a challenge for the professional**

From a number of informants with a strong "experience of context", we repeatedly hear ambiguous assertions concerning information on possibilities of support and aids. On the one hand, irritation is expressed about being offered aids that they do not feel they need, and on the other hand, irritation is expressed about not obtaining relevant information on possibilities of support and aids.

Johan has said the most distinctive words about the dilemma when he in a quote above says that it was good to know which aids existed, even if it was difficult and certainly nothing to write home about. The ambiguity in relation to aids can be seen as ambivalence in relation to taking charge of his situation. When the acquired deaf-blind people refuse to use a contact person or new aids, this can be an expression of an emotionally orientated mastering strategy. You tell yourself "I'm not in a bad enough way to need that contact person", and you become annoyed with the deaf-blind consultant who intimates that you could have such a need.

In the project, we have examples of informants who have been asked to obtain a contact person for several years and who, when she (sic) finally said "yes please", experiences that this opens up a whole new world of possibilities. She is today far more accepting of and well worded concerning her deaf-blindness than she was at the start of the project.

Here, she refused in the first interview to use a contact person, since she did not believe she needed one. In the second interview, however, she was allocated a contact person, and this has brought a great deal of joy to her life, since it has again become possible to take up sport, go to lectures or to the bank without having to be dependent on her spouse. She expresses great satisfaction with the arrangement and experiences being able to control it herself so that it suits her exact needs. Experiencing the possibility of doing many things as someone with acquired deaf-blindness seems to have pushed the informant in favour of a greater acceptance of her impairment.

It is easy to talk about the chicken and the egg problem. Refusal of practical support can be a matter of lack of acceptance of own impairment, among other things because you are afraid of all the limitations imposed by the impairment on your possibilities of opening up. At the same time, refusal means that it is confirmed to you that you have many limitations. If you had experience of for example using a contact person and thereby found that many things were possible in spite of your impairment, this could possibly lead to greater acceptance.

For some, the ambiguity is expressed slightly differently. They say that they would like to be informed so they can make up their own minds, but do not want to use assistance associations until it is absolutely necessary. This may for example be because they feel that the use of aids also comes at a price. There must be a reasonable relation between the endeavour that must be made to acquaint yourself with and learn how to use new aids, and the benefits of using the new aid. Each aid creates dependency: a guide dog must be looked after, also when you are going on holiday, a hearing aid has to be adjusted, and a wire loop cuts you off from other sounds in the room. Wanting to manage without aids can be a matter of wanting to manage on your own as universally as possible in life.

It is a great challenge for the professional to meet acquired deaf-blind people who have an ambivalent relation to their impairment in a way that shows them respect and increases their possibilities of acting competently in relation to their goals.

### **Starting point in people - not in aids**

A final dilemma is about the way in which the informants experience being introduced to aids. All professionals will probably say that they do not take the starting point in their own knowledge of aids, but in the person sitting opposite them. Unfortunately, some research shows that the relationship is quite the opposite. A study undertaken

by a group of British researchers showed for example that only 23 % of the patients in home care were allowed to complete their first sentence during a consultation, and that the interruption occurred after an average of 18 seconds. The researchers suppose that a tendency in the patients to put off discussing problems they themselves find troublesome may be due to the premature professional control of the conversation (Williams et al., 2000). It must be noted that this did not refer to patients with visual or hearing impairments.

As a professional, you possess knowledge and experience that you want to use, and this therefore is often focused upon. In a Danish project called “Young with impairments”, Sara Vafai-Blom points out some problems, experienced by the young with impairments in contact with the professional assistance apparatus. The problems, according to Vafai-Blom, are a result of the professional doctrine, understood to be conduct, values and standards that are developed over time, but in practice are perceived to be obvious and natural.

Problems arise when professionals focus on the problems to which there are solutions, and define the problem in a way that corresponds to the offers that are available. An example from Vafai-Blom’s project is the use of home care, where the system offers this as an offer of personal care, cleaning, etc., while the young impaired also see this home care as a social contact and therefore want to have a permanent person linked to them, who they can build up a relationship with.

Problems also arise when professionals focus on the present solutions. The young in the project asked for time to talk and process support. The doctrine was that it was more acceptable to grant help in form of an aid, a leisure activity or similar than to put aside time for process support.

*“The experiences indicate that the social worker ought to see himself / herself as an expert, not on the other person’s life (but perhaps in the handling of the circumstances), not in the way in which they are experienced, but perhaps in the way in which they can be changed, circumvented or mastered. Teacher Peter Westergaard Sørensen has proposed the use of the concepts “goal setter” (the client) and “path finder” (the social worker) in social work.”* (Vafai-Blom, 2003; 194).

Something indicates that the problems pointed out by Vafai-Blom will also be recognisable for many of the acquired deaf-blind. When the informants tell us about

situations where they felt that action was taken above their heads, this was probably not down to ill intent, but rather the professional not allowing herself enough time and composure to focus on the specific person opposite her. If we look at the competence to act concept, where it is a matter of being able to act in ways that put you in a position to pursue your own goals, the total focus is on the individual, not just on the professional's eye for the aids that may be relevant, but a more comprehensively-orientated eye for the type of overall situation that the informant is in, and the way in which a given aid will intervene in this. One example is the use of the white stick. To the immediate eye it is simply a practical tool to go out with, but the stick also means that you are signalling to your surroundings that you are blind. Several informants talk in depth about their considerations concerning and experiences with the white stick. Another example is the use of the computer. To the immediate eye, it is an ideal medium for the acquired deaf-blind person, but if you have negative experiences from school, your inclination to throw yourself into training in a medium in which reading plays a key role will be limited.

We have now focused on the informants' experience of obtaining information and practical support. This takes us further to look at their experience of needs for and evaluation of emotional support and support for self-evaluation.

## Emotional support and support for self evaluation

Emotional support is about showing recognition and perception of the acquired deaf-blind person's own experience of his situation and to help him to cope with and live with feelings-related crises. In concrete terms, it is the matter of perceiving yourself to be recognised and understood, feeling that there is someone who has the time to listen, even if communication may be difficult, and receiving confirmation that there are ways and possibilities – irrespective of how blurred the situation appears right now.

Support for self-evaluation is about contributing to reflection by the acquired deaf-blind person to put him / her in a position to relate constructively to his / her impairment.

One informant says very accurately why he believes that someone who has become deaf-blind to a greater extent than other people may need emotional support:

*“It is clear that irrespective of how well things are going for you, and how well you are functioning, a disease such as RP with a major hearing loss will be a constant mental burden ... for example, it's a great mental strain being in an unknown environment. It's probably true for most of the acquired deaf-blind that we are more dependent on a known environment – we are very locally confined.”*

The informants say that the experience receiving emotional support and support for self-evaluation from parents, family and friends and from professionals, psychologists in particular play a key role here.

### **Parents are very important – irrespective of age...**

We have, in connection with the informants' descriptions of the way in which they receive practical support in everyday life, already mentioned that the acquired deaf-blind person's parents often play an important role.

The relation to his / her own parents is probably the single parameter that proves to be the most important to the acquired deaf-blind person's “experience of context” and meaning in his / her life and for his evaluation of his / her own importance.

One informant who is married and has children says the following:

*“...I obviously think of my parents. It’s obvious that they have meant the most. It may sound a little abnormal, but that’s the way it is. I’ve probably been somewhat overprotected. That’s how you become when you have hearing problems, but I’ve had a great deal of contact with them, and they’re the ones I’ve naturally relied on the most. After them come my husband and my sister...”*

The parents have played and play a key role for everyone, irrespective of whether they are physically present in or absent from the informant’s life. For the youngest informant, it is still the parents who contribute support. The support consists to a certain degree of insisting on behalf of their child. The parents demand action from the professional level, which means that their hearing and visually impaired child gains more possibilities and experiences and (which is not less important) grow to realise through experience that it is worth insisting on setting your own aims in life. The young acquired deaf-blind person thus develops experiences of acting competently by experiencing his / her parents’ endeavours. For the adult acquired deaf-blind person, the support from the family can be expressed as help in day to day life. It can be anything from dropping by with the newspaper to giving extra tuition to the acquired deaf-blind person’s children to function as guides. Very briefly, it is of great significance to the individual’s “experience of context” and meaningful life if he / she has had parents who have fought for him / her, explained to him / her, made demands of him / her and loved him / her, to be the people they are today.

The three younger men with their own families who have chosen to live close to their parents describe primarily the way in which their parents offer practical support in everyday life, but they can only offer this support because there is a fundamentally close and mutually respectful relationship that has built up over many years, and that has developed to also accommodate the spouse and the grandchildren.

Another younger man who lives alone and is fighting the feeling of solitude is very careful to ensure that his relationship with his parents does not become too close. He lives near his parents and often talks to his mother, but expresses at the same time that he lacks a deeper connection. He visits his parents every weekend for lunch and via his mother keeps himself informed of the other family members’ activities.

Many mothers, particularly of the deaf and the deaf-blind, provide a negotiating function between the acquired deaf-blind and the rest of the family. This also means that the deaf



and the acquired deaf-blind experience a great loss when their mother dies. Two deaf female informants have lost their mothers during the project period, and they both speak of sadness that is difficult to overcome. The informants talk about the way in which their mother functioned as an important link to the hearing world and particularly to their siblings and other family members.

Many informants describe more or less directly that they have felt – or feel – dependent on their parents. This dependency can naturally be good and bad. If the parents protect against learning to cope with challenges, this will contribute to the child not being able to develop his own competence to act. For some informants, it appears that this dependency has led to the development of other social relations being difficult. We find an example of this in a 60 year-old woman, who only in connection with her father's death discovers that her spouse for many years can now take on the role of her closest confidante.

There are no sociological studies known to us that have been undertaken on the importance of parents in “adult children's” lives, but we find it worth noting that the parents of the group of the acquired deaf-blind apparently play a distinctive role way into the adult years, a role that we expect is greater than in the average population.

The importance of the parents in the life of the acquired deaf-blind can give cause for reflection on the role they can play when advising the acquired deaf-blind. Could family relations be involved in the individual conversations with the acquired deaf-blind, and could the acquired deaf-blind person be supported in having it his impairment and his consequential needs explained to the family?

### **An ordinary day with others appears to be emotionally supportive**

The informants who live together with their spouse and maybe children experience obtaining the emotional support that comes with having an ordinary day together with others. They say they do not need the family to show particular consideration in the form of encouragement or recognition, for example. Equality is a totally key concept. The informants emphasise not loading the spouse. This means that they sometimes show more consideration for the spouse than for themselves. Examples of this are when an informant does not use a wire loop for the TV, since it irritates his wife not to be able to contact him. Another example is a woman who prefers to have fluorescent lights and

all nick-nacks and loose items removed from the home, but respects the family's need for "it to be cosy".

As the visual impairment progresses, many do however experience having a particular need for the family's patience. Communication becomes difficult, and there are many misunderstandings.

Mogens is 57, deaf and has a very serious visual impairment, and lives with his wife who is hard of hearing. He says that it is very important for his wife to be able to use both sign language and tactile sign language, but that communication is nevertheless becoming more and more difficult:

*"She is probably noticing a change, since more and more tactile sign language is gradually needed between us. She notices that I misunderstand more often, that I don't understand things as easily as before. It's a general problem for those of us with Usher's that we find it easy to misunderstand... Yes, communication is becoming more long-winded and becoming more laborious, and we can become irritated and impatient, but I'm fortunate because my wife is very patient with me. It must be tiring having to look after a deaf-blind person. Think of all the little muddles and all the inconveniences with spilt coffee and glasses that overturn."*

Emotional support from spouse and family is to a large extent experiencing consideration being shown and seeing it as a mutual project to communicate as clearly as possible with one another.

The informants who live alone are vulnerable in relation to obtaining emotional support. If they themselves do not actively search for it, they are often left to themselves. This happened for example to Lone, who is 48, deaf and has a medium-level visual impairment. She has a feelings-orientated crisis in connection with her mother's death and feels alone:

*"I'm becoming terribly tired... when I come home, I don't have the energy to do anything ... I think it's hard to cry alone... I feel so alone, totally alone, nobody is here, no-one can comfort me. I find that difficult. Being alone with sorrow is hard."*

She generally describes her life as a fight, where solitude and depression are almost permanently present. There are other informants who have different ways of saying that they experience their situation as difficult, and that they need particular emotional support. One informant receives this support from the local priest with whom she has a few hours' conversation once a month. She experiences that the priest, by virtue of his declaration of confidentiality, his relationship with God and his knowledge of people's adversities, can listen and act as a special defence.

Another example of the way in which informants with a weak network need particular attention is Mads, who is 33, deaf and has a serious visual impairment. He has home care that has been reduced twice during the course of the project. This has consequences for Mads, who generally feels socially isolated.

*"I fancy talking to the home carer, but she has no time. I usually write on the computer, and she writes by hand. I'd like to hear a bit about the wind and the weather, what she has done over the weekend and suchlike. When she's with those who can hear, she can talk at the same time."*

Mads experiences needing to know his home carer and have a chat with her, but the local authority's list of his needs looks exclusively at the practical help he needs. They apparently do not see that the home carer could be of emotional support to a slightly vulnerable person.

It is very clear that the group of acquired deaf-blind who have no social network of family or friends, usually the single deaf and deaf-blind, are in a weak position in all ways. They generally have a weak "experience of context" and meaningful life and experience of being thrown around in a chaos of feelings that include anger, powerlessness and sadness. They do not meet people in whom their own experiences can be reflected upon, and nor do they gain information on offers that may be able to help to develop a stronger feeling of meaningful life, and nor do they have the energy required to receive them.

### **Emotional support from others with hearing and visual impairments is particularly important**

Some acquired deaf-blind people say that they receive important emotional support from friends, often people who themselves have a hearing and or visual impairment, since they really know what it involves. Anders says:

*“The best treatment comes from your friends and family. Even when I am well balanced, there are impressions and experiences that I need to have prepared. If I can’t talk about it, it accumulates in a way.”*

Marie has similar experiences. During the project, her youngest daughter moved away from home and this led to a psychological crisis. Marie had contact with a conversation group with other deaf people, which are led by a psychologist. It was very important to her:

*“I’m glad that I’ve agreed to be included in the conversation group. I feel that I benefit from exchanging experiences with the others and hearing that they have the same problems as myself... I actually feel like coming out with much more in the group, but the time is limited, so I have written down some keywords so I’ll remember them when we meet again.”*

Marie feels that she is getting to know more about herself through the stories of the other deaf people about their thoughts and considerations.

Petter tries as far as possible to live a life like everyone else and does not actively relate to his deaf-blind impairment. In the penultimate interview, however, he says that he and his family have been on a weekend course, where they have met others with the same eye disease.

*“I then noticed some of them falling into a chair and suchlike, and I’m so used to it being only me who does that type of thing, but there were others doing it as well. This was interesting for me to see, for if people fall into chairs, you sit and think “what’s wrong with someone who does such things, what’s wrong with a person, it seems as though that person is not particularly aware of his surroundings”. In a way, it wasn’t particularly nice to see, because you think of your own situation, and it doesn’t look good. Actually, I can’t allow myself to be indifferent to the area, I must probably be more aware of the people I have around me. Yes, I can now see myself, so I discovered the way in which it affects others.”*

Petter, when meeting others with problems like his own, is forced to relate actively to his impairment. It sounds as if a recognition process has started. Petter tells us more about his experiences of the course:

*"I also met someone there who had Usher Syndrome like me, but I only found this out when we were about to leave. I would probably have felt like talking to him a little, as we are in fact in the same situation. I could imagine getting in contact, but I don't have time to visit him, or he should come here."*

Petter here expresses his ambivalence. On one hand, he imagines being able to receive support for his recognition process by meeting someone else from the course, and on the other hand, he experiences not being able to find time to have this contact. Even though this is Petter's preliminary conclusion, it appears that the course has given important support to Petter's perception of his particular situation.

Some informants experience obtaining emotional support in being with their contact persons. Where some informants only use their contact person for practical activities in everyday life, others need the contact person as a friend and confidant. It can be strongly rewarding when there is a friendship between the acquired deaf-blind and the contact person, but it can also be a vulnerable relationship where there is much at stake for the acquired deaf-blind if the contact person withdraws or obtains other work.

### **Support from a psychologist can be very important**

A good 1/3 of the informants tell us of the way in which they in different ways have made use of a psychologist's help to cope with feelings-related crises or incomprehensible reactions.

In particular, the time when the acquired deaf-blind person has to say goodbye to his role as an active person on the labour market is described by many as a feelings-related crisis. Johan tells us of the way in which the 10 psychologists' conversations he was offered created totally new possibilities:

*"The psychologist I was given had an admirable capacity to reactivate me, to create some future possibilities and utilise my resources. She was very attentive to quality of life, that you could always have a good life even if you had an impairment. That should not prevent you from being able to receive training you couldn't undertake. When you are in the situation, it is incredibly important for you to meet someone who can push you and back you up."*

The conversations led to Johan starting new training within a completely different field, and he is getting a few more years on the labour market with this training. He later emphasises what this psychologist was able to do:

*“The ten conversations were with a psychologist who had made a big impression on me, as she saw me as a completely different person than just someone who had left a labour market. She saw some potential possibilities that should be used, and not just participating in a few short courses or comfort clubs and whatever there is now.”*

Other informants describe similar experiences of how important it was to get the emotional support that consists of being listened to and having someone focus on your own resources.

Some informants have also used the assistance of a psychologist to get to know more about and thereby better cope with incomprehensible reactions. One informant says that she has had problems with anxiety. A lecture gave her insight into the fact that something could be done. She has since participated in psychomotor training where she has learned to understand and react to her symptoms, and as an extension of this she has been granted 10 psychologist's conversations. These are used largely for her to reconcile herself with her diagnosis.

Another informant has suddenly experienced suffering violent stress reactions in the form of heart fluttering and violent stomach pains. He has via his own doctor been granted a psychologist's help, but has problems with finding a person with whom he can communicate with, since he does not wish to use interpreters in the conversations.

### **Experiences of and need for emotional support and support for self evaluation**

We can see that a childhood where the parents have been clearly supportive in relation to giving their impaired child the possibility of gaining experiences with succeeding is of great significance to the way in which problems are experienced and handled. Furthermore, an ordinary day with your own family has a positive effect on the acquired deaf-blind person's “experience of context” and meaningful life. A strong social network with broad contact with other people provides good conditions for developing a positive image of yourself and your situation.

This means conversely that the informants who have not experienced such a close, supportive parental contact are in a weaker position in relation to creating and developing a social network. This group includes a majority of informants who were born deaf. Here, we find several who do not have – or have not had – a one-to-one relationship and who struggle with experiences of solitude and low self-worth. Where the informants in this group have a weak network, this means among other things that they have not had anyone to compare themselves with and therefore have difficulty getting realistic images of themselves and their possibilities. They are at the same time more dependent on the professional assistance bodies, as well as having had fewer experiences of expressing their needs and placing requirements.

## **Experiences of support and advice from parents, family, networks and public authorities**

The informants' stories clearly show that their experiences of their needs and the support they receive are different. For the sake of clarity, let us allow Martin, Marie and Ottar to represent for a moment all of the acquired deaf-blind people who have participated in this project, i.e. they each represent a particular group of informants who have different levels of "experience of context" and different experiences of acting competently in relation to their goals.

### **Hans has limited experience of acting competently**

In this booklet, Hans has told of the way in which he is dissatisfied with his case handler saying that he himself must in the future coordinate the input concerning his impairment, and later on how long it took for him to get the mobile telephone he had applied for.

With these two stories, Hans has indirectly told us about his experiences of he himself taking the initiative and feeling recognised and listened to. They are limited. Hans is used to having others act on his behalf, and passively expects someone to do something.

His competence to act in relation to formulating requirements regarding the application for support is very limited. Hans' stories indicate that he has generally not experienced the situations he finds himself in as understandable and manageable. He lacks experience of what has to be done to change a situation and therefore expects others to take the initiative. It will therefore be problematic for Hans if he meets professionals who are waiting for initiatives from him. He needs the professionals with whom he is in contact with to focus on the way in which he can obtain experiences of his evaluation, actions, desires and needs of being important. This requires resources, since it takes time to use tactile communication with Hans. It is easier to propose initiatives and initiate them for him than it is to find time to talk to him about his evaluation. It also requires resources in the form of interpreters, contact persons, courses, etc., that can satisfy Hans' needs. However, if in the long term Hans is to become more competent in relation to achieving own goals, thereby gaining a higher level of "experience of context", there is no other way around it. Hans has the potential to act competently, but he needs many different types of resource if his potential is to be developed in a way that can make him more active in relation to his own needs.



Hans' situation is characterised by, as well as deafness, having a very advanced visual impairment. This makes contact with others difficult. A weak social network and consequential solitude means that he has a great need for support and advice from professionals. More deaf informants whose situation is similar to Hans' describe problems with obtaining interpreter assistance. Hans has for example no interpreter assistance at his work and is thus totally isolated from his colleagues. This contributes to the experience of isolation and to many misunderstandings.

Hans, and the other informants in similar situations, are likely to be experienced by the professional level as demanding, but with the background that the informants have, they have no experience of being able to act otherwise. Several have been "brought up" to be submissive and require treatment throughout a long life. It may sound extraordinary for someone to learn to require treatment, as no teacher or consultant wants to make their students or clients require treatment. However, research within this particular social area indicated that many of the measures that take place for groups in a weak social position have the effect of the client being asked to ask others for help. (Järvinen and Mik-Meyer, 2003, Mik-Meyer, 2002)

Hans and the other informants with similar experiences use both emotionally and problem-orientated mastering. They manage an unbelievable number of tasks in their everyday lives and describe the way in which for example taking the bus home from work in itself requires a problem-focused mastering strategy if there are delays, for example. One task for the professional includes making Hans see that he has those resources, which he does then use when the bus is late. He can take the initiative and act purposefully. The experiences from such situations must be used when it comes to expressing needs and acting purposefully in relation to them.

If we look at the involvement stage, there is no doubt that informants who in their stories say that they do not have experience of acting competently in relation to own needs mostly have experience of the lowest levels of the involvement stage. They either experience that action takes place above their heads, or they also receive information that they accept. They do not have experience of anything else. If their competence to act is to be increased, they need professionals to take the initiative to find out what they find important. The next step is to lay down a strategy together to achieve the goals and clarify who must do what for the strategy to succeed.

### **Solveig acts competently when she receives the necessary support**

Solveig, like Hans, is deaf, and she also has a serious visual impairment, but can in contrast to Hans still use her remaining vision a little. If we look at the progression of their impairments, they are similar to one another, but this is also where the similarity ceases.

Solveig tells us how she together with her deaf-blind consultant established a good cooperation with the local authority case handler, and how she increased her self-insight through a conversation group for the deaf. She has been followed systematically by some professionals, who had the knowledge and the skills required for Solveig to be able to achieve her goals.

Solveig has a family of adult children, where the youngest moved away from home during the interview period. Both of her children, her sister and her husband, who is deaf himself, can use sign language. She has thus had the supportive network around her that is so important to someone experiencing context in the events around him / her, and meaning in the life he / she lives. She has experience of significance being attributed to her conduct and evaluations, and she meets the professional with a social competence and authority that mean that she is listened to and taken seriously.

Her stories show that she has a fundamental “experience of context”. At the same time, it is clear that she needs support to act competently. She represents a group of informants who are looking for clearer information on how to make enquiries when they have a concrete need for support. Three informants with three different nationalities mention the need for increased interdisciplinary input. They lack specialists who can relate to double impairments, as they often experience meeting specialists in either the hearing or the vision area, but lack integration.

Solveig uses both emotionally and problem-focused mastering. The examples that are drawn on here show us the way in which she by virtue of the professional support she receives is in a position to act in a problem-orientated way when she faces crises in her life.

If we look at the involvement stage, the definition of need in Solveig’s case is in herself, while the professional backs her up. Later, when resources have to be paid for and strategies laid out, it is possible that the professionals use their knowledge and experience

to take initiative, but it is clear in Solveig's stories that she experiences joint action taking place. The initiatives are not taken above her head.

### **Freddy expresses needs, places requirements and follow up**

The last informant to be drawn on in this context is Freddy, who has a medium-level hearing impairment and a serious visual impairment. Freddy is well worded and has a strong social network around him. He knows the systems, formulates himself on their grounds and as rules receives the concrete information or support that he himself considers he needs. In each case, he does not expect the professional system to have to offer something else or more than the case is today. Informants with experiences like Freddy's emphasise that employees in the professional system must first and foremost be good listeners. The key is to be taken seriously when you express your need. This applies to all circumstances in life, irrespective of whether they concern the choice of a type of hearing aid, support in accepting your own situation, or respect for you yourself deciding when and how you will get in contact with other acquired deaf-blind people.

This group of informants is seeking practical support and information from the professional system, but sometimes lacks a possibility of obtaining collated and systematic information, e.g. on new aids and rights. They receive emotional support from the family and the social network, while several in this group have used a psychologist's assistance to develop their self-evaluation.

Freddy's way of demonstrating competence to act is similar to Solveig's, but there is a difference. Where Solveig is strongly dependent on the professionals around her backing her up and thus needs resources in the form of time and support to formulate and pursue her needs, Freddy acts independently and does not experience the need for support, for example, to obtain coordinated input in relation to his impairment.

People who like Freddy have a strong "experience of context" have experience of acting purposefully in ways that broaden their possibilities. They have developed this way of acting throughout their lives, where they have tried to find a reasonable solution to the problem they face. Sometimes there was success in progressing, other times they did not succeed, but each time they got to know more about what happened when they acted, what they found best, and they experienced that even if it does not always go well, no-one can act better on their behalf than themselves. In relation to the two types of mastering, this group of informants is largely characterised by use of problem-

orientated mastering. Freddy is a good example. Since the start of the project, he has had such physical nuisances that he has had problems with doing his work. In the third interview, he says directly that he does not know what he will do if he has to give up his very involving and demanding work. In the fourth interview (one year later), he tells us how he has managed to give up working and has accepted his new situation, and in the sixth interview he is on the way to developing a new identity as an active member of an organisation.

Freddy confronts himself with his problems, acts on that basis and finds new perspectives on his situation.

We can see a clear link between being able to act in a purposeful, problem-orientated way and to have accepted your impairment. If you accept yourself and your situation, which at the same time includes recognition of limitations and looking for possibilities, you expand your limits as regards to what can be done.

## **Hans, Solveig and Freddy - three acquired deaf-blind people with different experiences and needs**

If you meet Hans, Solveig and Freddy, they will be very similar to one another. They are all acquired deaf-blind people and they have to a certain extent the same need for aids, etc. but they will require completely different resources to support them in increasing - or maintaining - their competence to act. In addition, their situation is not static.

Hans can - particularly if he receives support for this - develop his experiences of acting competently. A contact person who has an eye for his needs and realistic expectations regarding his actions can help Hans to gain experiences that break the pattern he knows all too well.

Conversely, Freddy may also, if he for example is exposed to an accident, encounter a situation where he needs support to act competently. There is no advance assurance that Freddy will always manage these things himself and people like Freddy, who are used to doing things himself, may have difficulty in asking others for the help they suddenly need.

Competence to act and the ability to master challenges is not something that someone has at any one time and others never have. Everyone has the potential to be able to act competently and master the situations they encounter. Some have more experience with this than others, and experiences build on one another, i.e. if you have experience of taking the initiative yourself, it will be the most natural thing to do next time you encounter a problem; and vice versa, if you have experience of others doing something for you, you will then expect them to do something when you encounter a problem. Therefore, the great challenge is for professional consultants, teachers, case handlers, etc., who meet the acquired deaf-blind people in their work to have awareness of and openness towards the way in which the individual's competence to act can be strengthened in the concrete situation. This will occur by their meeting the client where he or she is and using their experience, knowledge and creativity in work with giving the acquired deaf-blind experience of themselves acting competently.

## **Worth thinking about**

- How can information and support be offered to relatives continuously in line with the progression of the visual impairment?
- How can the acquired deaf-blind person's network involve more support and advice?
- How can professionals help to increase competence to act?
- How can a forum be established for information on aids and be updated continuously and be available to everyone?
- How can the advice to a greater extent work on the basis of the acquired deaf-blind person's own experience of his / her situation?
- How can the possibilities of allowing the acquired deaf-blind person's perspective come forward in conversations concerning support and advice be increased?

## Summary

This booklet focuses on acquired deaf-blind people's stories of their experience of the support and advice they have received in connection with their impairment.

We focus on the informants' experience of:

- need for support and advice
- request for support and advice
- experiences of support and advice.

The concept of "competence to act" recurs throughout the booklet. This concept focuses on how support and advice helps to develop or maintain the acquired deaf-blind person's possibilities of acting competently in relation to his / her own goals. Competence to act and the ability to take control of challenges is not something that someone has and others do not. Everyone has the potential to be able to act competently and take charge of the situations he / she encounters. Some have more experience of this than others, and experiences build on one another, i.e. if you have experience of taking the initiative yourself, it will be the most natural thing to do next time you encounter a problem; and vice versa, if you have experience of others doing something for you, this is what your expectation will then be when you encounter a problem.

The informants' stories of practical support for coping with everyday life and emotional support to create experience of context and meaningful life lead to us singling out three ideal typical informants; Hans, Solveig and Freddy. There are many similarities between them, e.g. both Hans and Solveig were both born deaf and all three have serious visual impairments, Hans' being so serious that he is functionally blind.

We find that the difference between them lies in their personal experience and experience of context and meaningful life in the world around them. These different experiences concern both their individual experiences and the social resources that have been and are available to them.

Hans' stories indicate that he often does not experience the situations he finds himself in as understandable and manageable. He lacks experience of what is needed to change a serious situation, and therefore expects others to take the initiative. A weak social network and consequential solitude mean that there is a great need for support and advice from professionals.

Fundamentally, the possibility of obtaining assistance with interpretation is of crucial significance for Hans to be able to further his actional skills. Hans needs to meet professionals who take the time to offer tactile communication with him regarding the needs he himself experiences and, together with him, lay out strategies for these needs to be satisfied.

Solveig's stories indicate that she – among other things by virtue of the professional support she has received – has developed considerable experience of context in her life. She has during her life met professionals who have supported her experiencing, both that her needs were of significance and that she could act competently in relation to them. Solveig is looking for greater interdisciplinary investments and specialists with an insight into double impairments.

Freddy's stories indicate that he has substantial experience of context in his life. He is good at formulating requirements and is generally satisfied with the support he receives. He points out that employees in the professional system can never be too good to listen. The key is to be taken seriously when you express your needs. Freddy is looking for the possibility of obtaining collated and systematic information, e.g. on new aids and rights.

Finally, we see in the project that the extent of the informants' hearing impairment is of great significance to both the individual experiences they have and the social resources they come across. It is characteristic that we find among the informants who are born deaf find more who have problems with creating and developing a social network. This means that they are very dependent on the professional assistance bodies, and at the same time that this group has fewer experiences of expressing its needs and setting requirements



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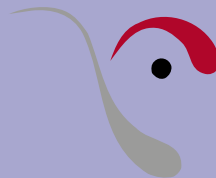
# EXPERIENCES FROM PEOPLE WITH DEAFBLINDNESS

*- a Nordic project*

The Nordic Project is a joint cooperation between the Nordic countries. 20 people with acquired deafblindness from Norway, Sweden, Iceland and Denmark have every year over a 5-year period, participated in interviews about the practical, emotional and social consequences of having a progressive hearing and visual disability.

The result is 6 booklets covering different subjects and containing very personal narratives and experiences of life, which gives the professional world a possibility of discovering or re-discovering the people, that the professional work is pointed at. The booklets talk about what is good – and what does not work. About being in the centre of a rehabilitation process or about the feeling of loosing control over ones own life, and where the strengths and weaknesses lie.

The booklets can be used as a source of inspiration for adapting or developing the work and the services offered people with deafblindness. The 6 booklets can create a deeper understanding of the individual perspective and the necessity of maintaining a focus on each individual person. Finally, the booklets can be seen as a historical cut in time, a documentation of the lives of 20 people.



Information Center for Acquired Deafblindness